5.9 (old 3.13.9) Hemoglobin Follow-Up Guidelines - Summary

INITIAL PATTERN	INTERPRETATION	FOLLOW-UP
		MANDATORY FOLLOW-UP
F only FS FSa FSC or FCS FC FSE or FES FD FDS or FSD FSV or FVS FAB Fast Hb >25% FEa FE* "XX" Bart's	β Thalassemia Major Sickle Cell Disease Sickle β Thalassemia Hb SC Disease Hb CC or C/β^0 Thalassemia Hb SE Disease Hb DD or D/β^0 Thalassemia Hb SD Disease Hb SVariant Disease Hb H or H/Constant Spring Hb E/β^+ Thalassemia Hb EE or Hb E/β^0 Thalassemia Alpha Thalassemia Major	Infants to be referred to a CCS Sickle Cell Disease Center for diagnosis and treatment. For Sickle Cell Diseases, penicillin prophylaxis should be started prior to 2 mo. of age. Confirmatory testing by the Hemoglobin Reference Lab is required for the infant; parent blood specimens are requested to aid in diagnosis. These patterns indicate a probable clinically significant disease which must be ruled out or confirmed by a CCS Sickle Cell Disease Center. *Most infants with an NBS result of FE will have confirmatory results of Hb EE, a benign condition. Confirmatory testing at the Hemoglobin Reference Lab is needed to rule out Hb E/Beta Thalassemia. Infants with E/Beta thalassemia are referred to a CCS SCDC for evaluation and follow-up. – no F or A present on NBS; if newborn dies, test parents (alpha globin DNA)
Transfusion indicated and pattern contains S, C, D, E, V or Bart's	Possible hemoglobinopathy (masked by transfusion)	Check for adequate pre-transfusion NBS. If not found, further testing on whole blood is required to rule out hemoglobinopathies. DNA testing can be done on WBCs as soon as blood can be sent to the Hemoglobin Reference Lab. If a hemoglobinopathy is confirmed, refer to CCS Sickle Cell Disease Center.
Hb A Only No transfusion indicated	Older baby, possible Inadequate sample or transfused	Unusual hemoglobin pattern for a newborn; may indicate older baby or transfusion. Verify transfusion status. If transfused, whole blood can be sent to the Hemoglobin Reference Lab, if requested by the physician, to rule out a hemoglobinopathy. If not older or transfused, sample is inadequate; obtain new NBS specimen.
		OPTIONAL FOLLOW-UP
Transfusion indicated with patterns of AF, FA or A only	No interpretation due to transfusion	Check for adequate pre-transfusion NBS. If not found, these results do not rule out a hemoglobin disorder or galactosemia because of transfusion. The ASC can help arrange for free testing at the Hemoglobin Reference Lab at the physician's request.
FCD FCE FCV FDC FDE FDV FEC FED FEV FVC FVD FVE *Patterns with 4-5 Hbs (e.g., FAED, FASV, F2AE, FA34, etc.)	No Interpretation possible due to unusual pattern	The clinical significance of these patterns is not clear. These patterns are expected to occur infrequently. * Patterns where <u>more</u> than three hemoglobins are present are considered uninterpretable. Further testing is needed to clarify the hb pattern. Patterns including A are most often confirmed as FAV (unknown hb variant trait). The ASC can help arrange for free testing at the Hemoglobin Reference Lab at the physician's request.
		HEMOGLOBIN TRAITS – VOLUNTARY FOLLOW-UP
FAS FSA FAC FCA FAD FDA AFS ASF AS AFC ACF AC AFD ADF AD	Sickle Cell Trait Hemoglobin C Trait Hemoglobin D trait Sickle Cell Trait* Hemoglobin C Trait* Hemoglobin D Trait*	Testing and counseling are available free of charge for family members by calling the Sickle Cell Trait Follow-up Program toll-free at (866) 954-2229. Counseling in person is available in a few areas. This service is voluntary. *These results assume no transfusion prior to testing. Free hemoglobin trait counseling and family testing are available by calling the Sickle Cell Trait Follow-up Program toll-free at (866) 954-2229.
		HEMOGLOBIN RESULTS WHICH ARE NOT FOLLOWED
FAE FEA FAV FVA	Hb E Trait Hb Variant Trait	No follow-up is provided by the Newborn Screening Program. These traits are usually benign. If symptoms appear (anemia) or there is a history of blood disorders in the family, refer to a CCS Sickle Cell Disease Center.
AF	No hemoglobin disease is apparent. However, this pattern can indicate transfusion. If transfused, the hemoglobin and galactosemia results are invalid; see transfusion follow-up protocol. (This pattern is seen in a number of newborns; older unaffected babies may also have this pattern.)	
FA	Results that appear to be normal and require no further action. This pattern assumes no transfusion and does not rule out the possibility of a thalassemia trait or rare hemoglobin variants.	

Please refer to Hemoglobin Follow-up Protocols for details of follow-up